Elder Choice:

How do older people make long-term care choices?

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A Report to the
Wisconsin Department of Health and Family Services
Division of Disability and Elder Services

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Preface

This document reports the outcome of focus groups, interviews and written surveys conducted in the spring and summer of 2003 by a consultant working for the Northern Area Agency on Aging under a contract with the Department of Health and Family Services. The consultant, Attorney Betsy Abramson, organized and facilitated focus groups, distributed and compiled surveys and prepared a draft of this report.

Every effort was made to solicit input from a wide range of interested persons. The document presents the comments and opinions of the focus groups participants and other respondents.

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Summary of Findings

During the summer and fall of 2003, groups of elders, family members and long-term care professionals were asked through focus groups, interviews and surveys to address the question of how, when and why older people make the decisions they do about long-term care. Attorney Betsy Abramson, under a contract with the Northern Area Agency on Aging, asked each group to address a series of topics, including:

- factors influencing elders in their choice of care;
- the role of and factors influencing families;
- the role of and factors influencing other professionals;
- factors influencing county workers; and
- factors leading to entering a nursing home or remaining in the community.

Participants identified many issues that impact when and how elders make long-term care choices, their likelihood of engaging in personal planning for future long-term care needs and the ability of the system to serve older people outside of nursing homes. Some of the key findings from this process are:

- Most elders have no idea what the term "long-term care" means. They will not/do not think about it until a need arises. This is true even for people already receiving some care and their family members. Also, unless they have had previous experiences with the county aging unit or social services, they do not think to call the county for information or assistance.

- Families do not call until a crisis occurs. Sometimes, given people's resistance to ask for help, they need to let that crisis happen.

- Most elders enter the long-term care system through a medical setting. They see a doctor because of forgetfulness or a fall or they experience a significant medical event such as a stroke and are hospitalized. As a result the incident secures a medical response. Doctors rarely know about community-care options and often do not understand the effectiveness of non-medical intervention. To these doctors, quality of life equals good medical outcomes equals safety equals nursing homes. On the other hand, doctors (and nurses) who have worked with counties have become champions of what social service home care interventions can accomplish.

- Many elders assume someone else will make decisions (and have a right to do so) about their long-term care—their family, the physician, a discharging hospital or a nursing home where they receive rehabilitation.

- There are several factors that make elders reluctant to seek assistance with long-term care needs, including:

    - Elders somehow see the need for long-term care as failure and may deny their needs or not even recognize their needs because the disabilities have progressed slowly and they have adapted to them.
    - Most elders treasure their privacy and independence—they do not want outside interventions or "strangers" in their home.

- Many elders are suspicious of social workers and publicly funded services. They fear that accepting any help is a "slippery slope" to a loss of independence.
- Several elders and most county workers report that Estate Recovery can be a disincentive to accepting community-based care. Many elders want to be able to leave an inheritance to their children and do not like the idea of owing a debt to the county when they die.
- Even if in a position to pay privately, many elders are frugal; they don't want to pay $10 an hour for chore services, much less $50 an hour for "case management."

- County staff report that having a nurse on staff is an asset when dealing with elders. They teach/translate medical language, diseases, medications, etc., to social service staff. Physicians and their staffs respect them and will work with them more readily, and at-home elders will talk (and show their scars) to them much more readily than to social workers.

- Elders can be inconsistent about the expected role of their families. Most expect that their families will provide care (especially homemaker and home maintenance services) but they are equally adamant that they do not want to be a burden.

- Families are generally overprotective and mainly concerned about safety. Workers often feel as if they are mediating between elders (desiring autonomy) and family members (desiring safety).

- Families may start by just providing services, never thinking that this is anything other than temporary. By the time they recognize that the situation is permanent, they may be burnt out and want to be *replaced*, not just given a respite.

- Spouses rarely consider themselves caregivers. They do what is needed because that is what a spouse does. This is somewhat true for families too. Accordingly, sometimes when a family is burnt out/spent, they will place a loved one in a nursing home rather than seek home care. If care can be provided at home, *they* should be able to do it, but if the care needs are too great for them, it must mean that a nursing home is needed.

- There are significant differences between long-term care for people with developmental disabilities and elders, both in philosophy and in the availability of services. Institutional placement is rare for persons with developmental disabilities, but elders with long-term care needs are routinely referred to nursing homes.

- Some factors that increase the chance of an elder entering a nursing home are: loss of mental competency; need for around-the-clock supervision; medical complexity; behavioral issues (aggression, wandering); falls; and lack of (or burn-out of) informal caregivers.

- Once in a nursing home for other than rehabilitation, an elder will only leave a nursing home with enormous advocacy on his/her part or family/others, if there are relocation funds available or if the court orders it. It also helps to have a home to go back to.

- Hospital social workers are *key* individuals. But their job is to get people OUT of hospitals, not necessarily into the right place for long-term. They need to discharge fast. Some of the

county workers interviewed mentioned that the Hospital Links program that existed in several counties a decade ago was effective, as long service funds were available.

- Aging Resource Centers are helpful to elders. Consolidating services for elders, simplifying funding and streamlining access are very effective where this has occurred.

- County workers were surprisingly non-judgmental about divestment. They recognized, matter-of-factly, that when you give a person only two choices – and both are bad – one shouldn't be surprised that they pick the one that puts their life savings in the hands of their children.

- County workers report service gaps that can impact their ability to serve elders. These include mental health and elderly transportation.

- "Pre-emptive moves," to smaller, more accessible arrangements (especially if they have long-term care available) that are elder-initiated, not in response to a time of crisis, can be empowering and satisfying for elders. The elders pick the place, do the sorting and tossing, see their cherished belongings being appreciated by others, make new friends and choose activities while still healthy. They feel good about saving their children from all those later decisions and problems.

- County social workers express frustration with waiting lists. The existence of a long wait list can deter elders from applying for services and they may not able to wait.

Elder Choice
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Introduction and Background

In the spring and summer of 2003, the Wisconsin Department of Health and Family Services contracted with the Northern Area Agency on Aging (AAA) to conduct a series of focus groups, surveys and interviews on elder choice. These activities were intended to help the Wisconsin Aging Network and other Wisconsin service providers better understand the factors and circumstances in which older people in Wisconsin make decisions about long-term care service needs. Northern AAA contracted with Attorney Betsy Abramson who organized and facilitated focus groups, distributed and compiled surveys and prepared a draft of this report.

Twenty-eight focus groups were conducted, including:

- county aging, long-term care and adult protective services staff (14);
- older people (8);
- family members of consumers of long-term care (2);
- Alzheimer's Association staff (2);
- ombudsmen (1); and
- information and assistance workers (1).

In addition to the focus groups, twelve attorneys and 82 county workers responded to written surveys. Individual interviews were conducted with six individuals who were believed to have a special perspective on the issue of elder choice.

Although the information gathering was somewhat informal, every attempt was made to reach a cross-section of interested individuals and to allow them to express their true opinions. The findings shed some light on how older people and those who support and assist them make decisions regarding long-term care. The results generally confirm both common perceptions and national findings.

Focus Group Findings

Elders

When and Where Elders Get Information

A major finding when talking with elders is that they do not relate to the term "long-term care." This is the vocabulary of social workers and not of elders or their families. Many did not know that the county aging office or county human or social services agencies might have information about services that would be relevant to them. Even in counties with Aging and Disability Resource Centers (ADRCs), elderly citizens were less aware of the services available through the ADRC than staff of those centers thought based on outreach efforts.

According to most elderly focus group participants, they would be unlikely to seek out information about long-term care services unless in a crisis situation. Even people who were

receiving services, did not show any greater interest in planning for potential future needs than did those with no current needs.

Only a small number of participants in the focus groups had done any future planning. This typically consisted of purchasing long-term care insurance or completing some type of advance directive. Even these individuals were not fully informed regarding what the policy or the directive really covered and whether it would truly support their needs and preferences. Many believed that their family would provide the support they would need. One participant said, half-jokingly, "my spouse is my back-up plan."

Participants were often unsure of where they would get information, but offered their thoughts about where they would start. Family members, friends, and neighbors were mentioned by many. They often mentioned they would seek out acquaintances with experience with a similar crisis or problem. The bad experiences of friends or acquaintances often colored their opinion of certain facilities or services.

Physicians were mentioned most often, but the few physicians who were group participants indicated that faith in doctors as sources of information on long-term care was misplaced. A small number mentioned clergy as a source of information. Other potential advisors on long-term care that were mentioned were insurance agents, financial planners or attorneys. (See page 12 for additional discussion of the role of professionals.)

Of the participants who were aware of county services, the county aging office was looked to as a good source for information. Sometimes the aging office was referred to indirectly as a particular person or function, like benefit specialist, or by the name of the building housing the aging office, like the Lincoln Center (the site of the Aging and Disability Resource Center in Portage County). Very few mentioned social or human services unless they were already somehow involved with that system.

A surprising number did not expect to have any say in decision-making should a crisis occur. Some assumed that the doctor would decide, while others thought the hospital would determine where you would go for care and that the rehabilitation facility would decide whether and when you could leave. At a minimum, most people thought that their family would make these major decisions on their behalf.

One of the retired physicians who participated in a focus group indicated that it is so hard for people to plan ahead because there are so many uncertainties. You "don't know how you'll be struck" or what type of support will be available when you need it. For example, will your spouse be around or able to help you? Will your children be nearby to help? He likened "long-term care readiness" to "reading readiness," it only sinks in when you are prepared to receive the information that is all around you.

Factors That Impact Elder Choices

Many elders view the need for long-term care as a kind of failure on their part. This is in contrast to the view of acute care. Since long-term care needs relate to the day-to-day activities they always did for themselves, the need for help is viewed as a burden on family and society.

Many participants noted that there was significant societal pressure to stay out of a nursing home. Both public perception and personal experience with friends or family paint a negative picture of nursing homes. They are "where you go to die." The information one gets about nursing homes often highlights the unpleasant stories. Nursing homes also represent a total loss of independence and control, which though understood by the elders spoken with, was still very undesirable. Some participants had experienced short-term rehabilitative stays and found them to be unpleasant experiences. Focus group participants had a less negative perception of community-based residential facilities (CBRFs) because of the efforts taken by many of those facilities to seem more homelike.

Participants indicated that, although the societal pressure and many people's personal preference was weighted towards staying at home, the system did not support it. Some of the elders who did volunteer driving or meal delivery cited appalling living conditions and extreme isolation for some of the people they helped. They expressed concern that some individuals were staying home in dangerous situations.

It became clear in the discussions that people do not always recognize the point at which they need help. Because elders often lose functional abilities gradually, they learn to cope and modify their behavior and environment over time. Admitting to a need for help can also be viewed as the beginning of a "slippery slope" to a nursing home and to a loss of privacy and independence.

Some specifically stated reasons for resisting services or other assistance in the home included:

- Concerns about cost.
- Fear of strangers in the home. This is especially true if helpers change frequently.
- Concerns about reliability of workers.
- Cultural and/or language differences.
- Not being able to control hours of service.
- Attitudes and demeanor of providers.
- Concerns about abuse/neglect/theft.
- Disrespectful providers.
- Loss of control over how things are done.

Many of these concerns stem from the overall sense that when you accept services you give up some power or control over your life. This loss of control in a nursing home seemed acceptable to many because the institutional setting appeared to call for it. However, losing that control in one's own home was difficult to accept. Concerns expressed by participants ranged from lifestyle issues like being able to get out of bed and get dressed at a certain time to seemingly minor issues such as where the tissue box was kept.

The issue of cost was important. Several of the elderly participants were resistant to the idea of paying for things they always did for themselves. Many assumed they could turn to family and friends for activities like chores and grocery shopping, but to pay someone to do it was problematic. Other services, such as case management, are so unfamiliar to many consumers that they do not see their value even if in a position to pay privately.

Several of the focus group participants reported the inconsistency in public pay programs for long-term care services. Many thought such services should be readily available, much like Medicare-paid services, but feel that going to the county for the services is too much like accepting welfare. This is confirmed by the estate recovery and lien laws that come into play when one accepts assistance from the county. Several participants mentioned estate recovery as a deterrent. They did not understand why they had to pay back the government for assistance that was funded by the taxes they had been paying for years.

In contrast, most felt very comfortable about accepting assistance from SeniorCare, Wisconsin's prescription drug program for seniors. The program responds to the universal problem of high prescription drug costs and has been implemented in such a way that participants contribute something based on their ability to pay. It was widely publicized and access was made relatively convenient. To elders, this program does not feel like welfare even though it is a means-tested entitlement.

The source of publicly funded assistance can also be a barrier. Elders generally viewed the aging department much more positively than they did social or human services. Many aging programs are available regardless of income and have provided positive experiences directly to those spoken with or to people they knew. Social services and social workers were viewed more suspiciously because of negative associations (e.g., they took my neighbor's kids away) or because of a lack of understanding of the role of social workers. Nurses conversely are familiar to older people and their roles are understandable, but long-term support agencies are just beginning to make extensive use of nurses.

Elders expressed a desire for a person at the other end of the phone line when they call for information or assistance. Systems that filter them through a list of selections are frustrating and may cause them to hang up. They do not like having to fill out lots of paperwork or to have to repeat their stories over and over again.

County workers indicated that elders responded more positively to services if the approach used had a light touch. Focusing on the outcome of staying at home was more likely to gain acceptance than just presenting a list of possible service choices. It also was effective to start small with a less intrusive service like home delivered meals.

Focus group participants expressed contradictory feelings about the role of families. While indicating that they expected, and perhaps were already receiving, help from family, they also expressed a concern about becoming a burden. The type of help appeared to be important—chores, shopping and help with meals being more acceptable than help with personal care tasks. Many had grown up in households that included an elder family member and remembered the change in family dynamic, so they were not inclined to impose themselves on their own children.

Some Differences Among Elders

Although based on anecdotes, some differences among sub-groups of elders were noticeable in the stories heard. These are observations made by respondents and are generalizations which will not apply in all cases.

Men, in general, seem more vigorous in their resistance to giving up their independence. They were more reluctant to move from the family home to an apartment or to give up driving. Many women viewed moving to an apartment as a relief from maintaining a big house or a chance to be less isolated (especially if no longer driving). Many couples, however, expressed a strong desire to stay together and to provide care for each other as needed. Women were less likely than men to view their caregiver role as extraordinary because it was a role they had always fulfilled in the family.

Rural folks had some different concerns and issues than did those living in cities. They were more concerned about everyone knowing their business if they accepted help. They also had fewer service choices, but perhaps more informal help from neighbors. Although isolation is an issue, they preferred to stay in the area where they were comfortable.

Focus group facilitators were also made aware of cultural issues, generally by county staff. While it is dangerous to stereotype any group, some cultural differences can make it a challenge to help people. One issue is race or ethnicity differences between service recipients and providers. Many elders have had minimal exposure to people who are "different" from them. This can lead to suspicion and to communication issues—both real language differences and cultural communication barriers.

Many ethnic groups present challenges due to a cultural context that is very different from the mainstream culture. For example, Hmong culture includes many beliefs that create barriers to providing assistance, including belief in alternative health systems and expectations related to the treatment of elders. Other cultures have norms that can conflict with accepted practice in long-term care.

Families

When and Where Families Get Information

Like the elders themselves, most family members (primarily adult children) do not seek information or assistance until a crisis occurs. At that time, they often want information and services immediately. According to county workers, family caregivers generally wait much too long and are seriously burnt-out when they finally call for help. They also report that contacts by family members pick up around holidays when adult children who live out of town visit mom or dad and become concerned by what they see. It is not uncommon to get a call on Friday from a worried son or daughter who wants services to start on Monday.

Families frequently are in the position of making decisions in the hospital. County workers indicate that this is the worst time because of the various pressures and the added confusion on the part of the elder due to his or her immediate health problems.

Many adult children gather their information via the Internet. Some have been referred or directed by their local aging resources or the Eldercare Locator. Others may start with a disease specific group like the Alzheimer's Association. Most counties estimate that from a third to a half of their calls come from family members and that many elders would never seek out services

on their own. The Aging and Disability Resource Centers report that family members often use their information and assistance services when they become aware of its availability.

Factors that Influence Families

As one would expect, each family is different. In many cases they are an important part of the person's support network. In other cases they may be a significant part of the problem. The extent of family support depends on the proximity of adult children, their financial status and their relationship with the person in need of help. Conflicts and disagreements among family members can complicate decision-making and may need to be managed by county workers when they are involved.

In the focus groups with elders it was clear that many of them expect to rely on their families for assistance with their care, even if that reliance is unrealistic. These expectations, however, are often limited to chore assistance, transportation and shopping. Very few want their adult children to have to help with personal care. The gender of the adult child also has an effect with it being somewhat more acceptable to receive care from a daughter.

The attitude towards providing care varies from child to child and also somewhat by gender. County workers reflected that daughters often appeared more patient and willing to provide hands-on care. Sons were more likely to want things "taken care of" by others. There are certainly many exceptions to this generalization.

The proximity of family is an important factor. In-town family members provide the most care and can appear to be less appreciated by the elder. They may bear a disproportionate share of the resentment for things like loss of driving privileges. Children who live out of town may downplay the need for help and believe the local siblings are overreacting or, conversely, they may believe the local family cannot provide adequate care and want the elder in a facility.

Elders themselves observed adult children were less likely to worry about them when both spouses were still living at home together. According to these elders, "as long as they see us together, we still look like mom and dad to them." Once a spouse dies, however, the worry level of the children increases.

County workers noted that family members were usually very focused on safety. Concerns include managing medicines, walking around the house and driving. Many are over protective and think only around the clock care will do even if it is not needed. County workers often serve the role of mediators between parents who want to maintain their autonomy, and families who want total safety.

Family members have many of the same views about in-home workers as do elders. They have fewer concerns about the loss of privacy and independence than do the elders, but worry a lot about reliability, abuse and financial exploitation.

Family caregiving, one county long-term support worker pointed out, is "accidental and incremental." It starts with a crisis and is usually expected to be temporary. It evolves from errands to homemaking to personal care. It is a very defining moment when a person realizes he

or she has moved from a spouse or child to a caregiver. Workers believe families wait too long to look for help and, as a result, are totally burned out when they come to the county. Once family members have hit their limit, they may become very demanding and want immediate action. They also may be less willing to accept in-home services to give them respite and instead want a residential setting that will totally replace the care they have been providing.

While elders worry about spending their children's inheritance on care, the vast majority of adult children do not share this concern. They want their parents to get the help they need. They can also be key in encouraging their parents to accept publicly funded help even if estate recovery and lien laws are part of the package. They do share their parent's concern about all the paperwork for a small amount of services.

In all of this there is a large overlay of guilt. Some families feel guilty that they cannot continue to provide the care that is needed at home. In some way, admitting the need for a facility can assuage this guilt. On the other hand, many families promise the elder they will not put him or her in a facility but then have to deal with the guilt of breaking a promise. Needless to say this is stressful and emotionally draining for families and for the elder.

County workers also report that many families do not understand why "the state" (Medicaid) will pay for care in a nursing home, but not in assisted living settings. They perceive that assisted living is nicer, does not carry the same stigma and may be less expensive. It does not make sense to them that the state pays for one and not the other.

County Workers (includes survey responses as well as focus groups' comments*)*

Factors that Influence County Workers when Working with Elders

One thing that was mentioned by workers was that the leadership in county agencies that work with elders is a significant factor. Whether in long-term support, adult protective services, aging unit or aging and disability resource center, a leader with a powerful vision, strong commitment and clear philosophy can make a difference to the line staff.

County workers who participated in the focus groups came across as hardworking and committed professionals. They were not ageist or looking for easy ways out. It was evident that county staff work hard and with great creativity to keep individuals at home and that they honor self-determination. They are very frustrated by the limitations on their ability to keep people in the community.

The three factors cited most frequently as having the greatest impact on worker ability to keep elders at home were:

- the availability of adequate and appropriate services, especially direct care workers;
- the availability of funding; and
- the attitude of the elder needing assistance.

County workers are often frustrated by the scarcity of direct care workers. Agencies may not be able to meet consumer needs because they do not have sufficient staff during regular hours, let

alone provide evening or nighttime assistance. Some agencies also have policies that get in the way of honoring consumer choice.

Workers in almost every county visited reported that transportation resources were lacking and a serious barrier to maintaining independence. Without adequate transportation options, elders are isolated. This isolation can lead to other problems such as depression or cause elders to do without because of reluctance to ask for help.

Another critical issue is the prevalence of mental health issues among elderly consumers cited by workers. These issues could have a significant effect on a home care plan and many long-term care workers did not feel competent to address issues or find appropriate services.

County staff indicated that funding for the Community Options Program and for home and community-based waivers is seldom adequate to serve everyone eligible for and in need of services. Workers are challenged to put together services to maintain a person at home until a "slot" is available. Every group of county workers noted the impact of waiting lists. They felt it was hard to do outreach and raise hopes when funding is not available. People are discouraged from even applying when told about the length of the list. Many people are reluctant to undergo an assessment when the wait is so long.

Often, when an assessment is done it reveals the need for a relatively modest amount of service, but people do not come to the county until they have few personal resources available to fill the gap. Aging units often try to fill these gaps, or as put by one worker, "hold them" with services such as home delivered meals. Aging units, however, also feel stymied by limited funds.

Funding was not considered an issue by workers in those counties where the Family Care program's Care Management Organizations (CMOs) can offer an entitlement to services for eligible individuals. Workers in those counties were enthusiastic about the difference it has made in their ability to do their jobs. In counties with a Family Care Aging and Disability Resource Center (ADRC), but no CMO (and no entitlement), information and assistance workers were frustrated by the lack of resources to back up their efforts at outreach. All ADRC staff saw the value of having a place where many resources were drawn together under one roof.

Another positive aspect of the outreach done by Family Care ADRCs and the resource center operations begun by some aging units is that they may reach people sooner. One social worker indicated that 70% of the people he saw did not go on a program, but that he was able to help them all in some way. These people may not need long-term care yet or they may be able to use personal resources to buy services. Regardless, they have a place to call should they need help in the future.

The ability to make contact and provide follow-up was also noted by aging units as critical. Many follow up even if a person refused services the first time. This is where consumer attitude comes into play. At the first contact an elder may not be ready to accept help, but if given time to think about and to become comfortable with the friendly person from the aging office, they may be receptive in the future.

Workers also noted that they had to remind themselves of the generational differences between themselves and the elders they serve. Attitudes about the role of daughters versus sons, money, marriage, county services, etc., can come up when working with elders. Workers did not feel they should be trying to update these attitudes, but should be respectful and accommodating about them.

County workers were surprisingly non-judgmental about divestment. While a few county directors and workers definitely shared some resentment about creative lawyers and "greedy kids" trying to out-smart the system, the great majority recognized, matter-of-factly, that elders were faced with two equally bad choices. An elder could spend all of her/his money on home care or spend some money on home care while giving some to family members and, in both cases, end up in a nursing home because of waiting lists.

Coming up again and again was the positive role nurses could play in the long-term support and aging field. Nurses can teach/translate medical language to social service staff. Physicians and clinic staff respect the nurses and will work with them more readily and easily than they do with social workers. Elders will also talk more readily with nurses because of their familiarity and comfort with the profession. Many perceived that elders more readily accepted advice and services offered by a nurse.

Factors that Influence the Decision to Enter a Nursing Home

One specific question asked of county workers was what factors led an individual to enter a nursing home rather than remain at home. A major reason cited, addressed above, was elders' and families' lack of knowledge about community services; these individuals believe that long-term care is synonymous with nursing homes. In addition, the factors county workers identified as leading to a nursing home placement can be categorized into several areas:

- Caregiver availability – This includes the general shortage of direct care providers, but also the inflexibility of some services or service availability. It is difficult to find 24 hour care when needed and some providers institute minimum visit policies that make it difficult to provide just what is needed when the person needs it.

- Family - Family caregivers wait too long to ask for help and cannot see options other than a nursing home. For a variety of motivations—safety concerns, peace of mind, geography, etc.—families prefer the all inclusive and relatively clear-cut option of a nursing home. Other families are not interested in providing help--perhaps due to family dysfunction or past negative actions by the elder such as domestic abuse or alcoholism.

- Physical Needs – When an elder is difficult to handle physically (e.g., two-person transfers needed for toileting), has daily incontinence or has a very complex and/or unstable medical condition, in-home care becomes more complex. Frequent falls can also prompt a nursing home decision.

- Cognitive Decline – Dementia and cognitive declines, especially when accompanied by wandering, confusion, medication errors, can require 24 hour a day supervision, and staffing becomes difficult.

- Behavioral Challenges – Wandering, sundowning, argumentative or aggressive behaviors (e.g., combative, name-calling), constant phone calls to family members during the day or, worse yet, at night can overwhelm or alienate providers and/or family. Substance abuse can also make it difficult to care for an individual at home.

- Elder Choice – Elders themselves occasionally choose a nursing home if worried about safety (physical safety such as medication or falls, especially falls at night), security, not wanting to be a burden on family members or if they feel lonely or isolated at home.

- Depression - While the overall issue of mental health was a concern that was raised with surprising frequency, the specific issue of depression was raised in response to this question. Workers identified situations in which depression causes individuals to self-neglect resulting in nursing home placements.

- Funding – Certainly one of the most significant issues, individuals' inability to pay for care on their own, the lack of Medicaid providers, and waiting lists for county services were raised in every single focus group, generally as the first response.

- Elder Attitude – Several county workers indicated that whether an elder remains at home is tremendously affected by the elder's attitude. They noted that elders who are persistent, but not stubborn, flexible and willing to accept some changes can most successfully age at home. One social worker put it quite succinctly: "If elders look at their disabilities as obstacles that they have been unfairly saddled with, and are resentful and bitter, it won't work. But if they look at their disabilities as issues that can be accommodated, they'll flourish and do just fine."

The county workers also noted that the longer an individual is in a nursing home, the greater chance he or she will remain there. Once an elder is in a nursing home for any purpose other than rehabilitation, an elder will only leave a nursing home with enormous advocacy on his/her part or by one or more family members, a county worker, a rare nursing home social worker, or others. And if the elder has no funds of his or her own, generally the elder will return to the community only if there are relocation funds available or if the court orders it. It also helps to have a house (and belongings) to go back to, although many workers mentioned individuals discharged to an apartment, assisted living or other smaller living arrangements.

The importance of an outside advocate (or agitator) cannot be overstated. The nursing home, all pointed out, has very little incentive to discharge individuals. Many of the county workers or ombudsmen who had formerly been nursing home social workers relayed that the daily question from administrators was "what's the census?"

Finally, many individuals mentioned the value of "pre-emptive moves," to smaller, more accessible arrangements – especially those where a variety of long-term care is available (e.g., independent apartments with assisted living and nursing facilities attached). Naturally very few of the workers had professionally come across these individuals but many were aware of elders in these situations. They agreed that "downsizing" moves that are elder-initiated and not in

response to a crisis, can be enormously empowering and satisfying for elders. The elders pick the place, do the sorting and tossing at home, see their cherished belongings being appreciated by others and make new friends and choose new activities while still healthy. And they feel very good about saving their children from all those later decisions and problems.

Role of Professionals

Throughout the course of the focus groups and other information collection activities, participants mentioned professionals who would be likely sources of information on long-term care alternatives. These are of special note because they might provide a natural focus for the dissemination of better information.

Physicians

Primary of all professionals noted by most of the focus groups was the physician. A significant majority of elders identified physicians as the professional from whom they would seek information regarding options and advice about decisions. Some indicated that significant decisions such as whether they would go to a nursing home would, and perhaps should, be made by the doctor.

A geriatric practitioner and numerous social workers lamented the fact that most elders enter the long-term care system through a doctor's office resulting in the medicalization of long-term care. Most doctors, they observe, are unfamiliar with community care options and do not understand the effectiveness of non-medical interventions. In a medical view, quality of life depends on good medical outcomes, which depend on safety. As a result, they may over-advise residential or institutional placements. Several social workers noted that some family members used the physician to force a move. In one group of family members, an individual indicated that it helped him to be able to blame the move on the doctor.

Some county staff indicated that older doctors appear to be less informed about community options. Younger doctors appear to be more aware of options and more willing to accept some risk. Staff from two of the ADRCs that were visited mentioned that nearby medical schools had their residents do a rotation in the ADRC. They were confident that this first hand experience would result in a new generation of doctors more cognizant and supportive of community supports. Some counties indicated that they intentionally cultivated "physician champions" for their programs.

Hospital Staff

In line with the reliance on physicians is a reliance on hospital staff, particularly hospital discharge planners. While a few elders mentioned this group, county social workers viewed them as *key* individuals. They noted that the job of discharge planners is to get people out of the hospital, not necessarily into the best place based on the individual's preferences. Other county staff complained that hospitals tend to use their own network, transferring patients to their own (affiliated) nursing home, swing beds or own home care agency.

Some social workers mentioned the "Hospital Links" pilot program in which county agencies established collaborative relationships with hospitals to coordinate discharges and follow up on

people expecting short-term rehabilitation stays in nursing homes. While in some cases the collaborations have continued, the existence of waiting lists has limited the ability of counties to respond quickly with services.

Clergy
Elders mentioned clergy with some frequency, but in a questioning way. After giving it some thought, most would acknowledge that clergy would probably not be familiar with services and options in the community. Others suggested that parish nurses might be more likely to have some insight and information.

Nurses
Although not mentioned by the elders themselves, county workers indicated that nurses were generally well received by elders and could provide information in a non-threatening way. The wariness many elders seemed to have for county social workers did not carry over to county or other publicly employed nurses. Elders are often more comfortable telling their story to a nurse, largely because of the familiarity with nurses in many situations.

County Aging Units
As mentioned earlier, elders who had past experience with aging units often mentioned that they would seek advice there. They did not necessarily refer to the aging unit itself, but to the building or the specific person with which they were familiar. Elderly benefit specialists were mentioned frequently as a great information source and problem solver.

Other Professionals
Occasionally elders mentioned attorneys, financial planners and insurance agents. They were mentioned exclusively in the context of financial decisions and not in terms of long-term care choices.

Comparison with Persons with Developmental Disabilities

The researcher for this project conducted interviews with four advocates for people with developmental disabilities. These were conducted because Wisconsin data shows that a larger percentage of publicly funded individuals with developmental disabilities are in the community than are elders with publicly funded long-term care. Three of the four interviewees also have significant experience with elders and with long-term care programs and were able to compare and contrast the approach to long-term care across the two populations.

Interviewees noted that people with developmental disabilities are seen as stable or possibly even becoming more independent. Elders are seen as being on a one way trajectory to having greater needs. They believe that providers and county workers may anticipate these declines and provide for a more restrictive environment earlier than necessary.

They also pointed out that children with developmental disabilities are connected, by law, with public entities. The public school system is responsible for education and services for children with disabilities until at least age 18 and perhaps age 21. Many children will have been involved

with county programs as well. School districts work with counties to transition individuals to the adult system and parents have many years of experience with advocacy.

Elders may never have any contact with the county human services system until a crisis occurs. They are more likely to enter the system through a doctor's office or the hospital. As a result services for persons with developmental disabilities operate from a social services model while services for elders have a medical focus.

These advocates also observed that there appear to be more services already developed for people with developmental disabilities of all ages, while many (especially smaller) counties have relatively fewer services for frail elders. This is especially true for private pay services.

Families of persons with developmental disabilities also appear willing to tolerate more risk than do families of frail elders. It is increasingly rare for families of persons with developmental disabilities to advocate for an institutional placement while ageism still makes institutionalization of the elderly acceptable.

Recommendations From Respondents

Although there was no specific question in the focus groups or surveys soliciting ideas for improvements to Wisconsin's long-term care system, many were offered. The list below is a compilation of some of the recommendations made by focus group and survey respondents. These recommendations do not necessarily reflect the opinions of the authors, the Northern Area Agency on Aging or the Department of Health and Family Services.

Paperwork and Program Rules

- Reduce paperwork and program rules to make it less intimidating and time consuming for people looking for help, especially if only in need of one service. In addition, program rules sometimes make it hard for people to get just what they need.
- Expand use of Pre-Admission Consultation (required for persons entering residential settings in Family Care counties). Although the consultations often occur after admission and may not prompt immediate action, consumers and family members may act on the contact at a later time.

Eligibility and Benefits

- Increase the asset limit for Medicaid and related programs. It has been set at $2,000 for single individuals for decades without any increase and provides little cushion for people trying to maintain their own home.
- Increase the income and asset limit for Family Care for single people.
- Allow Medicaid funds to be used for community-based residential facilities (CBRF or assisted living) in addition to nursing homes. It does not make sense to force someone happily living in a modestly priced CBRF to move to a costly nursing home that does not suit his or her needs or preferences.

- Provide greater flexibility regarding use of waiver funding for CBRFs. Decisions regarding appropriateness should not be based on the size of the facility, but on individual needs and preferences.
- Medicaid should provide coverage for certain situations of 24-hour care.
- Medicaid should use adult day care more.
- Medicaid should provide more benefits for transportation services.

Service/Provider Availability

- Develop strategies to increase the number of community resources and providers. Most counties need more of both. There is an especially serious lack of Medicaid providers because of reimbursement rates.
- Set a minimum wage for home care workers that will allow people to stay in the field.
- Create incentives for the development of a pool of volunteer guardians.

Outreach

- The state needs to begin a statewide public education effort to encourage elders not to wait to make plans for long-term care. This should include educating adult children about information, assistance and care available, care needs, the aging process and possible role reversal when caring for aging parents.
- The state needs to encourage early diagnosis of Alzheimer's disease since early intervention can greatly assist the patient and his or her family.
- There should be targeted ads or public service announcements about long-term care between Christmas and New Year's.
- There should be a public education campaign about the need for elder care volunteers.
- County social services need to find doctors who can become champions of home care and social service interventions to assist in educating other health care providers.
- County-initiated outreach should make clear that ADRC services are available to all individuals – regardless of income.

Training

- Agencies that work with elders should provide internship/rotations for physician and nursing students to learn more about the value of social service intervention in maintaining individuals in the community.
- Medical schools should provide curriculum to physicians that teach student physicians that home care works.
- Wisconsin's aging and long-term support networks need training about identification, appropriate referrals and services for the growing problem of mental health issues among the elderly, especially depression, hoarding and addictions.
- The long-term support network and domestic violence networks need to work together to address problems of domestic violence in community long-term care situations.

Approaches

- County programs should be cautious in using sophisticated phone technologies with elderly clients who still prefer to speak with a live person on the phone.
- County workers should approach elders by telling them that they are "here to see what we can provide you with to keep you safe and happy in your home," without ever mentioning a move.
- County workers should, when offering services to elders, assure them that they can accept the services for a "trial period" only and terminate services whenever they want.
- County workers meeting hesitation or resistance from elders should try to "start small," with services like Lifeline, home-delivered meals, some transportation services or a small amount of homemaker services, permitting an elder to develop trust.
- County workers should whenever possible, make a second (or third or fourth) offer of assistance, every few months, to individuals who initially refuse services.
- Counties should work to increase coordination between medical providers and social workers.
- Long-term care should be removed from county "welfare" departments and merged with aging units or a separate long-term care unit.
- The state legislature should enact legislation that would require a pre-admission review before elders are admitted to a nursing home.
- County benefit specialists for the elderly, being tremendously trusted by the elderly, should be trained to provide more information about county-based long-term care services and to encourage clients to accept referrals to county long-term care programs.
- Put more focus on prevention and early intervention.
- The "Powerful Tools for Caregivers" Program has been extremely well received and should be continuously used throughout the state.
- The program name of "Family Care" should be changed to a name that more properly reflects what it is – a program that provides long-term care services to elders and people with disabilities, regardless of family involvement.

Funding

(Although listed last in this document, this was the area with the most often identified and the most strenuously-made suggestions.)

- Expand Family Care statewide.
- If Family Care is not immediately expanded, add significant funds to the Community Options Program (and related waiver programs) to eliminate waiting lists.
- Provide reasonable per diems. End rate disparities based on waiver type.
- Provide more funds for relocations and for on-going support for consumers once relocated.
- Funding formulas should recognize that case management is critical, and that it takes time, money and skills.
- Provide more funding for benefit specialists.

Conclusion

Comments from the focus group participants and survey respondents suggest that government and other interested entities might do a better job of getting people to recognize the potential need for long-term care as we age and to make some effort to prepare for that likelihood. People would benefit from information before a crisis occurs, but at a minimum, need access to complete information and options counseling at decision points.

Unless cognitively or psychologically impaired, elders are competent adults and have a right to make their own decisions, yet even many elders accept that someone else will make long-term care decisions for them. Although county workers appeared to recognize that they work for the consumer, they often find themselves balancing the preferences of the elder with those of family members and medical professionals.

Increased flexibility in the long-term care system to ease people into the system with low impact services may enable elders to remain independent and healthy longer and perhaps avoid crises. This may make the use of more intensive services acceptable in the future. Aging units and aging resource centers can be a resource for these types of "easy touch" services.

Working together, the Department, the aging network and county departments of social and human services could develop models to enhance opportunities for elders to be aware of and exercise their choices in long-term care. To be effective, these models need to involve private entities and include outreach to people before they enter the public system, preferably while they are able to make financial plans.

APPENDICES

APPENDIX A
List of Focus Groups Conducted

Consumers

- Bureau of Aging and Long Term Care Resources – Aging Advisory Committee – held in Madison
- Brown County
- Green County
- Iowa County
- Oneida County
- Portage County
- Waukesha County
- Wood County

Family members of consumers

- Manitowoc County
- Winnebago County

Alzheimer's Association representatives

- Green Bay and Neenah offices
- Madison office

Ombudsmen In-Service

- Statewide group, held in Madison

Information and Assistance Workers

- Northeast regional group – held in Green Bay

Aging, Long-Term Support, Adult Protective Services and/or Resource Center staff

- Green Lake County
- Kenosha County
- LaCrosse County
- Marathon County
- Milwaukee County
- Outagamie County
- Portage County
- Richland County
- Rock County
- Trempealeau County
- Waukesha County
- Waupaca County
- Waushara County
- Wood County

APPENDIX B1
Discussion Questions for Older Consumers
Focus: How and Why Do Older People Make Decisions About Where They Receive Long-term Care?

1. **INFORMATION.** Research says that most individuals will have some kind of long-term disability at some point in their later years (for example, a stroke, dementia, physical disability, etc.) Have you thought about this at all? If so, how, when and from where have you gathered information about your long-term care options? If you haven't yet done so, how do you think you will in the future?

2. **WHERE WOULD YOU WANT TO GET CARE AND WHAT KIND?** Most research also finds that most older folks would prefer, if possible, to get any needed care in their home or apartment rather than moving. Is that true for you? What factors or concerns do, or will impact you, when making a decision about long-term care?

3. **COST.** How much do you think the kind of care you would want might cost? How do you think you would pay for the care you might need?

4. **ROLE OF FAMILY.** What role does or will **your family** have when you make (or will make) your decisions about long-term care? To the extent your family will have a role, what factors or concerns do you think will impact your family? How much consideration have, or will you give to your family's concerns or preferences?

5. **ROLE OF PROFESSIONALS.** In addition to family members, which **professionals** have already, or do you think will, provide you with advice or input? Why? What **factors** do you think these professionals would think about?

6. **OBSTACLES?** Think about what you hope will be the way (setting, provider) you will receive long-term care. What obstacles, if any, do you think there may be to this working out as you desire?

APPENDIX B2

Discussion Questions for Family Members of Older Consumers

Focus: How and Why Do Older People Make Decisions About Where They Receive Long-term Care?

1. **INFORMATION ABOUT LONG-TERM CARE OPTIONS.** How, when and from where have you gathered information about your family members' long-term care options (what kinds of services and supports they will accept and where they will receive them – at home or moving to a different place)?

2. **FACTORS INFLUENCING YOUR ELDER LOVED ONE.** What factors or concerns do, did and/or do you think will impact your loved one, when making his or her decisions about long-term care options and settings?

3. **FACTORS INFLUENCING YOU, THE FAMILY MEMBER.** What factors or concerns do, did, and/or do you think will impact **you**, when helping your family member make a decision about long-term care?

4. **ROLE OF PROFESSIONALS AND FACTORS.** In addition to other family members, which **professionals** have already, or do you think will, provide your family with advice or input? What are the **factors** that you think these professionals would think about? What impact or influence did or will these professionals' opinions have on the ultimate decision?

5. **ROLE OF COUNTY WORKERS**. What factors do you think impact **county workers** who may be in a position to advise, counsel or determine a service setting or service package for you?

6. **OBSTACLES?** Think about what you hope will be the way (setting, provider) your loved one does, or will continue to receive long-term care. What obstacles, if any, do you think there may be to this working out as desired?

APPENDIX B3
Discussion Questions for APS, LTS and/or Aging Resource Center Staff
Focus: How and Why Do Elders Make a Decision About Where They Receive LTC?

Please spend a few minutes jotting down some of your thoughts on the following questions. In answering these questions, please consider:

- How do elders (and their families) **get information** about long-term care options?
- What factors influence the decisions of elders to either remain at home with supportive services or enter a nursing home (or other facility)? For example, you might consider….

✓ Financial issues?
✓ Experiences with county staff?
✓ Input from family?
✓ Input from professionals, such as physicians, clergy, teachers, others… (such as…?)?
✓ Personal concerns (such as….)?

1. What factors or concerns impact the **elder**?

2. What role does the **family** have? To the extent it does, what factors or concerns impact the family?

3. What factors impact you, as **county workers** in counseling elders and their families and/or designing service packages?

4. In the situations you have seen where a client ***leaves*** the nursing home or other institution and returns/moves to a community placement, what factors made that happen? (From the elder, from the family, from the county, from….?)

5. If you worked for the county *before* your Resource Center began, how do you think your answers might differ before and after your Resource Center was implemented?

APPENDIX B4
Discussion Questions for Alzheimer's Association Staff
Focus: How and Why Do Elders Make a Decision About Where They Receive LTC?

Please spend a few minutes jotting down some of your thoughts on the following questions. In answering these questions, please consider:

- How do elders (and their families) get information about long-term care options?
- What factors influence the decisions of elders to either remain at home with supportive services or enter a nursing home (or other facility)? For example, you might consider….

✓ Financial issues?
✓ Experiences with county staff?
✓ Input from family?
✓ Input from professionals, such as physicians, clergy, teachers, others… (who?)?
✓ Personal concerns (such as….)?

♦ If you have done any work with consumers in Family Care counties, do you see any difference between Family Care and non-Family Care counties?

1. What factors or concerns impact the **elder**?

2. What role does the **family** have? To the extent it does, what factors or concerns impact the family?

3. What factors impact **county workers**?

4. What factors impact **you** in counseling elders with Alzheimer's and their families about where they receive LTC?

5. In the situations you have seen where a client ***leaves*** the nursing home or other institution and returns/moves to a community placement, what factors made that happen? (From the elder, from the family, from the county, from….?)

APPENDIX B5
Discussion Questions for Ombudsmen
How and Why do Elders Make a Decision About Where They Receive LTC?

Please spend the next five minutes jotting down some of your thoughts on the following questions. In answering these questions, please consider:

- How do elders (and their families) get information about long-term care options?
- What options are presented, by whom and when?
- What factors influence their decision to either remain at home with supportive services or enter a nursing home (or other facility)? For example:
  - financial issues?
  - experiences with county staff?
  - input from family?
  - input from professionals, such as physicians, clergy or others (who…?)?
  - personal concerns (such as….)?
- For those of you serving Family Care counties too, do you see any difference between Family Care and non-Family Care counties?

1. What factors or concerns impact the **elder**?

2. What role does the **family** have? To the extent it does, what factors or concerns impact the family?

3. What factors impact **county workers**?

4. In the situations you have seen where an elder LEAVES the nursing home and returns/moves to a community placement, what factors made that happen? (From the elder, from the family, from the county….)

APPENDIX C
Discussion Questions for Developmental Disabilities Advocates
Focus: How and Why Do Elders Make a Decision About Where They Receive LTC?

Please spend a few minutes jotting down some of your thoughts on the following questions. In answering these questions, please consider:

- How do **elders** (and their families) get information about long-term care options?
- How do **people with developmental disabilities** (and their families) get information about long-term care options?
- What factors influence the decisions of **elders** to either remain at home with supportive services or enter a nursing home (or other facility)? What factors influence the decisions of **people with developmental disabilities**? For example, you might consider….

✓ Financial issues?
✓ Experiences with county staff?
✓ Input from family?
✓ Input from professionals, such as physicians, clergy, teachers, others… (who?)?
✓ Personal concerns (such as….)?

♦ From your work with consumers in Family Care counties, do you see any difference between Family Care and non-Family Care counties?

1. What factors or concerns impact the:

Elder	Person with a Developmental Disability

2. What role does the **family** have? To the extent it does, what factors or concerns impact the family of a/an:

Elder	Person with a Developmental Disability

3. What factors impact **county workers** serving clients who are:

Elder	Persons with a Developmental Disability

4. In the situations you have seen where a client ***leaves*** the nursing home or other institution and returns/moves to a community placement, what factors made that happen? (From the elder, from the family, from the county, from….?)

Cases involving Elders	Cases involving people with a Developmental Disability